

ORIGINAL ARTICLE

Living at home with eating difficulties following stroke: a phenomenological study of younger people's experiences

Marianne E Klinke, Thóra B Hafsteinsdóttir, Björn Thorsteinsson and Helga Jónsdóttir

Aims and objectives. To explore and describe the experience of eating and eating-related difficulties in stroke survivors living at home.

Background. The ability to consume food and to take pleasure in eating is an essential part of life. For people with stroke, eating difficulties are frequent. A phenomenological perspective of stroke survivors' experience of eating difficulties exceeding the acute stroke event and in-hospital rehabilitation is missing.

Design. A qualitative study founded on the Husserlian descriptive phenomenology.

Methods. Colaizzi's seven phases of data analysis provided a systematic approach to explore 17 in-depth interviews from seven participants and how eating difficulties influenced their daily lives.

Results. Eating difficulties revealed themselves in participants' relationship with the outer world in far-reaching disruptions of habits, capacities and actions. Four key themes illuminating the eating difficulties emerged: (1) preserving dignity by not conveying serious problems, (2) staying vigilant to bodily limitations, (3) stepping out of the security zone and (4) moving on without missing out. The findings exposed that eating difficulties might not only lead to serious consequences such as malnutrition but also, and equally importantly, lead to losses in the existential, social and cultural lifeworld.

Conclusions. The experience of eating difficulties entails an *ongoing* readjustment process, which is strongly influenced by interactions with other people. The findings suggest that individualised long-term support is needed to facilitate the use of helpful strategies to manage eating difficulties.

Relevance to clinical practice. The long-term losses that people with eating difficulties experience are not reflected in conventional screening tools and interventions. To avoid haphazard identification presupposes professional knowledge of how eating difficulties are woven into daily life. This knowledge may inform innovative nursing strategies reaching beyond immediate rehabilitation. Partnership-based practice may provide an important framework to establish unique needs and to mobilise relevant actions and resources.

Key words: adult nursing, eating problems, nurse–patient relationship, phenomenology, rehabilitation, stroke

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Authors: Marianne E Klinke, MSc, PhD Student, RN, Clinical Nurse, Faculty of Nursing, University of Iceland, Eirberg and Department of Neurology, Landspítali University Hospital, Reykjavik, Iceland; Thóra B Hafsteinsdóttir, PhD, RN, Associate Professor, Department of Rehabilitation, Nursing Science and Sport, Faculty of Medicine, Rudolf Magnus Institute, University Medical Centre Utrecht, Clinical Health Sciences, Utrecht University, Utrecht, The Netherlands; Björn Thorsteinsson, PhD, Phil, Research

Scholar, Institute of Philosophy, University of Iceland, Reykjavik; Helga Jónsdóttir, PhD, RN, Professor, Faculty of Nursing, University of Iceland, Reykjavik, Iceland

Correspondence: Marianne E Klinke, Clinical Nurse, Faculty of Nursing, University of Iceland, Eirberg, Eiríksgata 34, 101 Reykjavik, Iceland. Telephone: +354 895 0173.

E-mail: klinke@simnet.is

What does this study contribute to the wider global clinical community?

- Offers insight into the ongoing challenges that particularly younger stroke survivors with eating difficulties are faced with in their daily lives at home.
- Provides a model for understanding inhibiting and facilitating factors of the experience of eating difficulties—facilitating factors that might be considered for nursing practice.

Introduction

Stroke has become an extensive health burden and is the primary source of disability in people living at home (Miller *et al.* 2010). Despite improvement in treatment and decreasing mortality rates, stroke might leave patients disabled and cause considerable interruption in their experience of living a fulfilling life (Mayo *et al.* 2002, Hong & Saver 2010, Kubina *et al.* 2012). This situation makes it essential to explore strategies to improve meaningful support. Stroke survivors' ability to maintain treasured eating-related activities may be central for their well-being (Perry & McLaren 2004). However, only one qualitative study has described patients' experiences with eating beyond six months following stroke (Carlsson *et al.* 2004).

This study attends to stroke survivors' experiences related to eating difficulties after discharge to their homes and provides insight into approaches that healthcare professionals might take to assist them to accommodate to their difficulties.

Background

The sudden nature of a stroke renders it impossible for people to prepare steadily for changes, and stroke survivors have expressed overwhelming feelings and disruption in adjusting to a new situation in life (Hafsteinsdóttir & Grypdonck 1997, Salter *et al.* 2008). An enduring and frequent problem following stroke which is closely connected to functional, social and personal well-being, is eating difficulties (McLaren & Dickerson 2000, Westergren *et al.* 2001a, Poels *et al.* 2006). Eating difficulties occur when the innumerable constellations of symptoms imposed by the stroke lead to modifications of food preferences, ability to prepare food, consumption of meals and the capacity to enjoy eating (Jacobsson *et al.* 2000, Perry & McLaren 2003a,b).

Researchers have targeted areas that might influence individuals' eating experience following stroke. Hence, stroke survivors have expressed feelings of shame and embarrassment because of adverse reactions from their surroundings. Such feelings are frequently related to changes in appearance, need for support during mealtimes and difficulties with social exchanges over the dinner table (Jacobsson *et al.* 2000, Ekberg *et al.* 2002, Kumlien & Axelsson 2002). The social aspect of eating has been emphasised in the literature, and stroke survivors who live alone tend to eat less than those cohabiting (Perry 2004). Following stroke, many individuals need to confine their diet to easily consumable items, often of a changed texture, to be able to eat safely. If the new food items diverge considerably from

normal preferences, however, this might cause diminished appetite and subsequently less nutritional intake (Axelsson *et al.* 1984, Jacobsson *et al.* 2000). Correspondingly, alteration in the sense of taste and smell can cause food usually favoured to suddenly appear unappetising (Axelsson *et al.* 1984). Feeling secure and safe while eating is also important, and individuals might eat an insufficient amount of food if they fear suffocation (Jacobsson *et al.* 2000, Ekberg *et al.* 2002, Kumlien & Axelsson 2002). After discharge from hospital to home, eating difficulties may extend to practical problems such as shopping and cooking (Carlsson *et al.* 2004, Westergren 2008, Medin *et al.* 2010a,b).

Most interventions to identify eating difficulties have focused on screening for malnutrition and dysphagia (Klinke *et al.* 2012). Coherently, alleviating nursing strategies primarily have revolved around education and optimising feeding techniques or eating position, such as ensuring correct texture of food, protecting clothes, improving oral hygiene and adjusting eating devices, within hospital and rehabilitation setting (Westergren *et al.* 2001b, Kumlien & Axelsson 2002, Perry *et al.* 2012).

A framework for individualised interventions based on patients' unique needs is missing in clinical care after discharge to own home, a desideratum which might be explained by the sparse amount of qualitative studies. A review of the literature revealed six qualitative studies illuminating various perspectives of challenges that people face in the process of regaining normalised means of eating (Table 1).

The existing qualitative studies strongly indicate that eating difficulties collide with key aspects of life and that stroke survivors find it difficult to incorporate these difficulties into daily living (Carlsson *et al.* 2004, Medin *et al.* 2010a,b). However, none of the studies have focused on younger individuals' experiences—a perspective that might be important to cover because younger people often provide a more accurate picture of living with health-related difficulties because their experience is not blurred by comparison with their contemporaries (Vuorisalmi *et al.* 2006). With the exception of the study by Carlsson *et al.* (2004), existing studies only treat stroke survivors that were followed for no more than six months. Therefore, these studies may not reflect the deeper existential and social aspects of eating difficulties over time. The importance of attending to areas beyond physical factors of eating after discharge from care facilities have recently been emphasised (Klinke *et al.* 2012, Medin *et al.* 2012, p. 586). This phenomenological study provides insight into alterations related to eating difficulties that stroke survivors experience in their daily lives with reference to their social, physical, existential and cultural lifeworld. The overall aim may be

Table 1 Qualitative studies on eating difficulties

Author/country	Participants/age/setting	Methodology	Eating experience
To locate qualitative studies of eating difficulties, a structured literature search was performed in Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus and Web of Science using the following search terms Stroke (MeSH) combined with eating (MeSH)/deglutition (MeSH)/ingestion (MeSH) and the nonMeSH terms difficulties, problems, experience, feeding and community. The search was limited to articles in English, adult patients and published from January 1990–December 2012			
Jacobsson <i>et al.</i> (2000) Sweden	<i>n</i> = 19 stroke patients Mean age: 69 years Acute setting	Exploratory study design Semi-structured interviews Compared narrative results with structured observation of eating performance	Categories of eating difficulties identified: Fear of choking Discomfort in mouth and throat Thirst Discomfort from food Lack of appetite and feeling sickness Change of taste Shame about one's own appearance Humiliating feeling of dependence Fear of anticipating recovery
Perry and McLaren (2003a,b) UK	<i>n</i> = 113 stroke patients Mean age: 67.5 years Home-care setting six months following stroke	Exploratory study design Semi-structured interviews Thematic analysis in: QSR NUD*IST 4*	Main themes: Getting back to normal Getting by Six categories of difficulties identified: Physical eating impairments Effect of impairments Appetite and weight Practical factors, shopping, cooking and food Psychosocial factors Social eating
Carlsson <i>et al.</i> (2004) Sweden	<i>n</i> = 3 Mean age: 70 years 1.5–2 years following stroke Community	Explorative case study Repeated in-depth interviews	Core theme Striving to live a normal life Three subthemes: Abandoned to learn on one's own Experience of losses Feeling dependent
Medin <i>et al.</i> (2010a) Sweden	<i>n</i> = 14 Mean age: 74 years Three months poststroke Community	Grounded theory – comparative approach Semi-structured interviews	Core theme Striving for control; incorporated aspects of (1) eating properly and (2) eating safely Four subthemes: Analysing the consequences Being careful when eating Avoiding activities Needing help from others
Medin <i>et al.</i> (2010b) Sweden	<i>n</i> = 13 Mean age: 75 years six months following stroke Community	Grounded theory – comparative approach Semi-structured interviews	Core theme Desire to master the eating situation Some still experienced negative feelings especially when eating with others, while others had regained former routines

*Nonnumerical unstructured data indexing software.

synthesised as follows: To explore and describe the experience of eating and eating-related difficulties in stroke survivors living at home.

Methods

Husserl's descriptive phenomenology provided the philosophical underpinnings for this qualitative study. The

process of arriving at phenomenological insight can be described in two moments, the epoché and the reduction (Zahavi 2003, p. 44–46). Bracketing is a methodological preparatory measure for the researcher to achieve the epoché. The researcher uncovers his/her presuppositions and describes them as clearly and painstakingly as possible (Colaizzi 1978a). In reduction, the researcher arrives at phenomenological insight when the experience moves into a

more temporal description encompassing the past as well as future anticipations (Zahavi 2003). Colaizzi's (1973, 1978a,b) method guided the study preparation and analysis and was selected to provide a clear and practical way of approaching the descriptive phenomenology.

Participants

A purposeful sample of seven stroke survivors in Iceland, two women and five men, below 65 years of age, was included in the study. Phenomenal variation sampling ensured rich coverage of experiences likely to be important with respect to eating difficulties (Sandelowski 1995). Therefore, participants varied according to their deficits: some had obvious difficulties, whereas others had less apparent ones. Further inclusion criteria were that the participants could express themselves, which was based on the assessment of a speech language therapist (SLT), that a minimum of six months had passed since the stroke and that they lived at home with a significant other.

Data generation

Data collection commenced in November 2010 and ended in March 2011. Verbatims were generated from in-depth audio-taped conversations, and two to three face-to-face meetings were established in a location of the participants' choice. Five participants were interviewed in their homes and two in a homey location at a rehabilitation centre.

Before the interviews, the term 'eating difficulties' was discussed with the participants and conceptualised as: 'any activity and emotional requirement and relations, which alone or in combination interfere with the process of preparing food, transferring food into the mouth, chewing and swallowing' (Klinke *et al.* 2012). During the interviews, the researcher and the participants shared a light meal or coffee/tea with bread. Open-ended questions were used to bring the experience of eating difficulties into a clearer focus (Table 2).

All interviews were recorded and lasted between 25–75 minutes. Adequacy of the study sample was thought sufficient when no new themes emerged from the data analysis.

Ethical consideration

Ethical approval was obtained from the Icelandic Human Research Ethics Committee (no. 09-058-S1), and the National Bioethics Committee was informed about the study (no. S4413). All participants signed written consent, and it was emphasised that participation was voluntary and could be withdrawn at any time. Potential participants were expected to have communication problems. Collaboration was therefore made with an SLT who initially contacted the participants to ensure that they could articulate considerably well. If people expressed willingness to participate, they were contacted by the researcher (MK), who further explained the study and encouraged questioning. People with stroke might utter strong emotions that are not as powerful as expressed (Annoni *et al.* 2006, Ferro *et al.* 2009). The interviewer (MK) drew on her clinical experience in dealing with emotional liability and also remained alert to changes in speech, slowness or other evidence indicating exhaustion in the participants (Carlsson *et al.* 2007).

Data analysis

Colaizzi's (1973, 1978a,b) seven nonlinear stages to approach data were employed (Table 3).

Accordingly, interviews were transcribed promptly and expanded with clarification of nonverbal cues. Then, they were listened to or read several times to get an overall impression of their content. Significant statements were identified and transferred into index cards. Statements containing similar responses and remarks were grouped and their meaning extracted. Nonverbal expressions significantly influenced the exact wording of meanings. Theme clusters were shaped by the meaning units, some ambiguity existed

Table 2 Examples of open-ended questions used in the interview

Describe a situation that stands out for you in which you have experienced eating difficulties. (Having in mind thoughts, feelings and perceptions at the time)
Can you describe what has changed in eating since the stroke? Can you illustrate this with some examples? (Having in mind food preparation, longing to eat, the eating situation, socializing, eating with familiar/unfamiliar people)
What has been the most important problem for you in relation to eating?
Describe how you have established a new daily life with your eating difficulties. What have you learned? What has helped you the most?
Are there any positive aspects?
Probes were used to elaborate and achieve further details on the experience such as: What is it about this ... that makes you say that? or Can you explain that in more detail? I can see that you... [observations made while sharing a meal/coffee], can you elaborate on that?
Are there any more important aspects that you want to mention?

Table 3 Colaizzi's (1973, 1978a,b) seven nonlinear stages of data analysis

Colaizzi stresses that these seven stages of phenomenological data analysis are not definitive and that they practically overlap and should be adjusted depending upon needs under individual circumstances

Stage 1: Acquiring a sense of each transcript

Stage 2: Extracting significant statements

Stage 3: Formulation of meanings

Stage 4: Organising formulated meaning into clusters of themes

Stage 5: Exhaustively describing the investigated phenomenon

Stage 6: Describing the fundamental structure of the phenomenon

Stage 7: Returning to the participants

to where relevant meanings belonged which caused some overlaps between the clusters. An integration of meanings and theme clusters were written into an unequivocal description of eating difficulties and the structure identified. Finally, participants were (re)visited and presented with a summary of their individual interviews. The main purpose was to elaborate further on their individual experiences and to confirm that the summary reflected core issues of their experience. Substance was added, but no new themes were identified.

Trustworthiness

The researcher conducting the data collection (MK) has been engaged with eating difficulties in people with stroke for 14 years and was familiar with most of the participants from her clinical work. It was therefore important to be particularly vigilant of presumptions and make them explicit. Presumptions and emerging study results were

challenged and exposed to ongoing triangulation throughout the study period with the help of experienced researchers (HJ, TBH, BT). To facilitate bracketing and intuiting, the researcher (MK) kept a reflective diary and all researchers took time to dwell over the data (Colaizzi 1973, p. 98, Gallagher & Zahavi 2012, p. 30).

Results

The participants were 34–64 years of age (mean 53 years) and between seven months and eight years had elapsed since the stroke (mean three years). The experience of eating difficulties reflects far-reaching disruptions of habits, capacities and actions, which are woven into daily activities. This is illuminated in the four themes of the exhaustive description: (1) preserving dignity by not conveying serious problems, (2) staying vigilant to body limitations, (3) stepping out of the security zone and (4) moving on without missing out. The interplay between the theme clusters is illustrated in Fig. 1.

Preserving dignity by not conveying serious problems

Eating in the company of others was the venue where difficulties became perceptible. Participants only admitted to minor problems even if considerable amendments were obvious, such as staying focused while eating, avoiding certain food, making changes in food preferences and avoiding having meals with others. Eating difficulties were minimised and weighed against the overwhelming impact of the stroke, where participants initially had faced their own mortality and uncertainties of whether they would be able

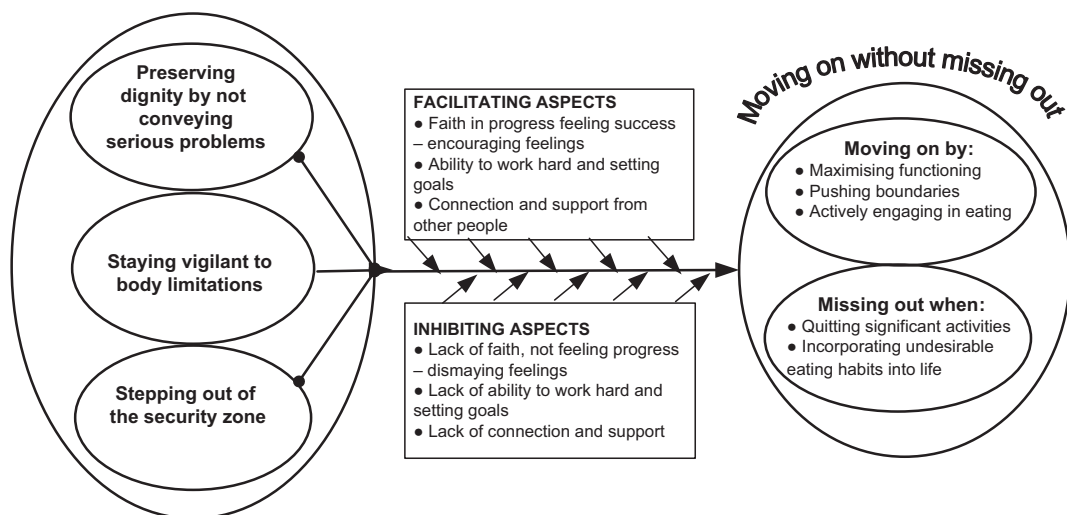


Figure 1 Interplay of eating difficulties.

to return home. Hence, eating difficulties on the surface represented a minuscule problem: 'I'm extremely relieved to have survived this. This is not a guaranteed outcome, that you are [alive]. I'm just relieved to be at home. This is a victory'.

Because eating was a way of presenting themselves as persons, it was important to maintain a good appearance and to eat in a socially acceptable way. To do so, participants avoided food that needed to be cut, circumvented the use of special aids and frequently cleansed themselves around the mouth. If the participants were not able to live up to their own expectations of how to behave, they felt humiliated:

I'm wiping [my mouth] after every mouthful. I don't do it as much at home, but if I'm elsewhere I'm extremely conscious that there is no food dripping. I don't realize if I have tomato sauce all over the place. I don't sense it. I prefer to eat [pause] not like a child.

The participants would feel excluded if they did not receive compassion from others. Conversely and involving some ambiguity, they were afraid that their restrictions would make them become an inconvenience:

I will not accept any special treatment. Nobody asks anymore whether I want to eat something different. I do not need any special treatment, special food, or anything. I do not want people to be bothered by having me for a visit.

Initially, participants refused help and concessions even though they longed for it. This could cause feelings of loneliness and isolation. As time passed, the difficulties moved to the background:

I found it uncomfortable. I wanted to eat like I did before, it was humiliating to cough and letting someone else cut the dinner up for me. I'm tremendously relieved that this part of my life is over and that I'm moving forward.

Staying vigilant to bodily limitations

The changes that transpired after the stroke did not allow for the luxury of not contemplating eating. Participants used a variety of methods to maintain a good outward facade, such as being selective of food and slowing down while eating. This made them capable of controlling the body and appearing competent and independent. During the interviews, some participants pretended to drink coffee, lifted their cups to their mouths and took sips without swallowing. This was an attempt to maintain normal cadence in socialising. Compared with other neurological deficits that the participants dealt with, they had more

control over the eating difficulties, and they could make choices: 'I can partly influence the swallowing, *when* I eat and *with whom* but [in comparison] I cannot control the neurological pain in any way'.

Being well aware of reduced eating abilities, the participants knew the consequences of being inattentive while eating: 'You always face it when you forget, you get punished. It does not happen very often, yes, this is learning the hard way'. The penalty of inattentiveness was a constant reminder to remain alert at mealtimes. The resolutions were to prepare themselves mentally and physically by staying focused, to rest, to eat slowly and to remind themselves to do only one thing at a time: 'If I'm eating something I always have to think about it. I always think—now I have done enough chewing and can proceed to swallow and so forth'.

Other bodily limitations curtailed the participants' ability to perform in eating situations, such as problems with handling cutlery, difficulties in shopping, clumsiness, impaired sensation and sense of temperature, fatigue, lack of initiative, diminished appetite and feeling vulnerable to injury while eating or preparing meals: 'The dizziness actually is bad when I turn around in the kitchen—it's like being on a boat. You need to be careful with the warm food—this is very uncomfortable'.

Favourite food might taste differently and disordered sensation of food in the mouth resulted in less pleasure in eating. External features such as cold weather and spicy food also interfered with the participants' eating: 'It's almost like I'm allergic to spicy food. I used to do a soup with chilli and things like that but it does not work for me now. I have a coughing fit and everything goes haywire'. When choking, participants held their nerve and pretended to be calm. Panic reactions exacerbated eating difficulties and provoked fear in other people, and therefore, it was paramount to keep one's composure. Participants had learned by trial and error what worked, such as coughing or drinking water, so the food eventually would pass:

I relax. I'm not afraid, I'm naturally not calm on the inside but it matters to 'hold your nerve'. That's the number one thing, because if you panic everything stands still, nothing will come, just relax [deep breath]—then you always get a little bit of air, and then, then it comes.

Stepping out of the security zone

The participants' home represented a secure zone where they could relax and be free from contemplating their appearance. At home, they could eat at their own pace,

withdraw from conversation and accept assistance from their relatives as required. Some were not prepared to leave this sheltered environment and became precautionous of inviting guests who might disrupt the security. Also, diminished endurance required consideration: 'You need to conserve yourself for things that really matter. It's a different attitude now. Before the stroke, I just jumped into everything, but now I consider whether I have the energy to do this and that'. Some participants completely ceased meeting others for dinner because they found the consequences too risky: 'I would say that I have some social phobia now. I socialized a lot before, always met new people, but now, it exhausts me. I rather want to be at home'. When dining with people, apart from the closest relatives, the main aim was to stimulate the mind. While stimulated, they needed to remain focused on one thing at a time so that their eating would not become interrupted. For others, dining outside the home was a victory even though they worried that other people would receive wrong impressions:

When I meet old acquaintances whom I have not seen [since the stroke], it is not always easy. Then I want to be myself, like before [but] you need to live a normal life [pause]. I go out. I don't care whether people stare at me.

Nevertheless, 'If there are more [people beside the closest family] then I kind of withdraw'. Explaining obvious consequences of the stroke was relatively easy if they really looked like they had had a stroke. In comparison, intangible problems like fatigue or handling simultaneous stimuli only received limited understanding, even from the closest relatives: 'Unfortunately I find that my symptoms are invisible, people cannot see that anything is wrong. Often there is no understanding'. Choking or inappropriate laughter or crying made other people uncomfortable. Security was therefore found in having the closest relatives in attendance because they were sensitive to preventing undesirable occurrences. To alleviate embarrassing and unpleasant situations, a variety of methods were used, such as humour: 'My wife laughs, but other people—that's more difficult. But when she laughs, she breaks the ice. She calls me crybaby which I find beautiful'. Cruelty from other people sometimes materialised, making the participants feel vulnerable:

I was totally exhausted. I was really starving and needed the energy. We went up to the dining area, me and my co-workers. I thought that I would never be able to get the food down. It was totally stuck. Anyway, I was just coughing and coughing. It took me an hour to finish the meal. My employer came twice and they stared at me when I was coughing. Well, I'll tell you this is

imprinted into my memory. When I came out, I couldn't believe what I saw. They were making fun of me, jumping around, coughing—I did not think that people could be that way.

This individual left this work place immediately and never returned.

Moving on without missing out

The participants had learned to appreciate many things that they had taken for granted before the stroke. Eating had gone from an almost unconscious act to a valued activity, which provided an important forum for challenging their abilities. Influencing their own health by eating healthily provided a victorious feeling of control, whereas an incapability of balancing adequate intake was demonstrated in feelings of inadequacy and contemplations on how it hampered progress, such as considering weight gain versus mobility. Participants not only wanted to preserve what they had, but also wanted to improve their present condition: 'I don't allow myself to be sloppy about it [my health], not considering its importance. I have been threatened and I'm aware that anything can happen'. Progress required relentless work and was measured by either establishing personal benchmarks for evaluating their own performance, for example when comparing themselves with poorer-functioning individuals or by validation from others such as family, friends and healthcare professionals. This network was essential in restoring a normal life and being able to move on:

I cannot imagine how it is for people who do not have a family to go through this with. I would have had a difficult time moving on. I try not to look back, it might be a little bit of a denial but it is for the best.

A standstill was feared, whereas steps forward gave the participants an ecstatic feeling, enabling them to remain optimistic about recovery:

It was the first food that I ate since the stroke [more than one year had passed]. I was very cautious and worried that it would not pass the throat like I had been experiencing. But I ate it, and it was really pleasant. This was the first food, I mean 'real' food, not the mashed one. It was delicious. I recall that I woke up during the nighttime, I couldn't sleep. I was so excited that I had been able to eat. I felt that I could conquer the whole world. Eating normal food and feeling appetite was a sign for me and my family that everything would turn out to be okay.

Similarly, unrealistic expectations about one's own capabilities resulted in discouraging feelings and reduced

progress, especially when aiming at resuming prestroke activities:

I was always struggling to do stuff in the same way as before. Now, I just do different things. I have filled the void, I'm very satisfied but it still hits home when I'm confronted with something that I'm not able to do.

Even though the eating difficulties brought along negative feelings and sometimes resulted in isolation, they still, with time, became an integrated part of the participants' lives. 'Eating difficulties is just a part of the whole package. I'm just thankful for every day no matter how it is'. For some, the struggle with many losses pushed forward a consequential development process that could be seen as personal growth:

Initially I did not want to eat with others because I felt embarrassed by needing help. Now I realize that there are some things that I cannot control no matter how hard I try. Sometimes you need to stop contemplating the whys and wherefores. I have been presented with new areas of life and it is up to me to get the best out of it. Basically, I'm doing the same things as before but in a different way. Instead of cutting up the food my wife does it for me, I don't talk to others while eating—just afterwards and so forth [pause]. Of course I needed to push the boundaries several times before this felt natural.

The degree to which it is possible to move on without missing out is reflected in facilitating and inhibiting aspects in the participants' surroundings as well as their ability to create a new meaning in eating. Eating difficulties are interactive, and in spite of moving on with life, the stability is fragile. The enjoyment of positive responses from the surroundings and functioning in a maximal way might change if stroke survivors experience disruption—such as compromised eating ability and if other people show their eating difficulties less understanding.

Essential structure of eating difficulties

Stroke survivors' search for a normal rhythm in eating is characterised by quandaries. These revolve around acknowledging the consequences that eating difficulties create while minimising serious problems in spite of their wide-ranging impact. Stroke survivors envision limited options to their eating problems, and unnecessary impediments are created when restructuring of skills primarily occurs by trial and error learning. With time, reluctance and apprehension of the eating difficulties move to the background. Nevertheless, eating is not a completely involuntary act, and new situations are approached care-

fully. In a temporal manner, they are related to memories of unforgettable experiences with eating difficulties, prior choices of handling difficulties and the anticipation of consequences. Feelings of safety, predictability and control are highly valued. Eating involves more than personal abilities and perceptions; it is an interpersonal event that presupposes interaction with others. This relationship with the outer world can either build up the stroke survivor or restrain possibilities for getting the most out of life.

Discussion

This study adds new depth to existing literature, which has emphasised eating difficulties in immediate care and rehabilitation with a main focus on interventions on functional difficulties (Kumlien & Axelsson 2002, Westergren 2006, Perry *et al.* 2012). Findings were similar to those of other qualitative studies in illustrating how social aspects of eating difficulties, rather than the eating process itself, were of prominent importance when needing integration into daily life (Jacobsson *et al.* 2000, Carlsson *et al.* 2004, Medin *et al.* 2010a). However, the time frame has been extended—indicating the *ongoing* significance of eating-related challenges for the stroke survivors' social integration and psychological and physical well-being. Traditional screening tools and interventions are not sufficient when assisting people to get the most out of their lives with eating difficulties because of their main emphasis on functional problems (Klinke *et al.* 2012). Acknowledging that eating difficulties may be complicated to detect because of their close interconnectedness with many everyday-life experiences makes it of paramount importance to establish alternative ways to capture those difficulties. To identify eating difficulties and to promote individual suited solutions therefore presupposes an in-depth assessment. As proposed in prior literature such assessment could include conversations and/or questionnaires (Jacobsson *et al.* 1996, Westergren 2006, Medin *et al.* 2010a). Furthermore, as may be apprehended from the results of this study, innovative interventions should include opportunities for long-term engagement between nurses, patients and their families.

The process of adapting to a new familiarity with eating can be understood through Merleau-Ponty's (1945/2012, p. 100–140) description of the corporal schema where the body of habit provides a framework for normality. Thus, previous benchmarks on eating still exist in the immediate time following stroke, but the capacity of the body to fulfil these normal standards have been disordered. With enduring performance, the body recal-

brates, and new patterns are gradually incorporated. The habit body is polarised by the repetition of tasks and undesirable solutions, such as eating alone would become integrated if performed over and over again. To facilitate incorporation of 'good habits', stroke survivors should be encouraged to use appropriate helping aids and accept concessions.

Sufficient encouragement contributed significantly to the experience of moving on for participants in the study. Attainable goals are also vital considering that idle periods where everything is at a standstill are discouraging. In these periods, which can occur repeatedly, people are in particular need of support in discovering new challenges with which to engage, to counterbalance the tendency to focus on what has been lost (Hafsteinsdóttir & Grypdonck 1997, Burton 2000, Perry & McLaren 2004).

Changes in taste have been identified as a hindering aspect for stroke survivors' ability to enjoy eating (Jacobsson *et al.* 2000, Perry & McLaren 2003a). Nevertheless, this problem has not been incorporated into a routine assessment tool. The participants in this study stressed how aberrations of taste often remained a persistent problem. Additionally, the participants also described oversensitivity to spicy food and found that cold weather sometimes exacerbated neurological problems, especially their swallowing performance. Problems related to cold weather and spicy foods have, to our knowledge, not been described in people with stroke previously, a phenomenon that merits research attention in future.

Eating played a central but often concealed role in the well-being of the participants. The social aspects of eating were of prominent importance underscoring the need to focus on what eating signifies to the individual. Participants mainly learned by facing up to their own mistakes. This elucidates a deficit in care and reinforces the need for post-discharge follow-up visits over an extensive period of time, even in situations where people appear resilient and seem to be managing well.

Study limitations

This study enhances knowledge on eating difficulties following stroke, and the findings may be used to guide future care and research. To our knowledge, no such study using a first-person perspective has previously been performed. The researcher shared a light meal with the participants, which provided a unique view of eating difficulties.

The participants were comparatively well off in terms of effects of the stroke, and they were living with a partner. A

common platform of understanding the findings is therefore limited to this fact—underscoring the importance of not generalising the findings to all stroke survivors.

Implications for practice

To avoid haphazard identification of eating difficulties presupposes professional knowledge of how those difficulties are woven into daily life. For people with stroke living at home, partnership-based practice might provide an important framework to establish unique needs and to mobilise relevant action and resources. This is achieved through a relational dialogue where three main components are activated: 'family involvement', 'living with symptoms' and 'access to health care' (Jonsdottir & Ingadottir 2011, p. 928). These factors call attention to how nurses might support patients with eating difficulties, as reflected in Fig. 1. Hence, nurses should apply strategies that enhance independence in eating, social and family connections, ability to push boundaries (e.g. eating with others), goal setting and feelings of progress—which in turn reinforces the joy of eating, social participation and so forth. Recently, authors have suggested that interventions to support people with stroke in their social reintegration with follow-up should be provided until six months poststroke (Kirkevold *et al.* 2012). However, when eating difficulties are present, this follow-up time should be stretched even further.

Conclusion

Stroke patients may not overtly articulate problems related to eating difficulties which means that nurses should be in the forefront in advocating a systematic approach to address these problems. Nursing care should not only discover and appreciate stroke survivors' unique personal experiences; it should also open up possibilities into long-term engagement between nurses, patients and their families. The benefits of partner-based services for people living at home with eating difficulties following stroke need to be studied. Furthermore, additional long-term qualitative studies on the experience of stroke survivors, particularly of those who are more affected by the stroke and those who are living alone, are needed.

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Disclosure

The authors have confirmed that all authors meet the ICMJE criteria for authorship credit (www.icmje.org/ethical_1author.html), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or

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Conflict of interest

No conflicts of interest are declared by the authors.

References

- Annoni JM, Staub F, Bruggimann L, Gramigna S & Bogousslavsky J (2006) Emotional disturbances after stroke. *Clinical and Experimental Hypertension* 28, 243–249.
- Axelsson K, Norberg A & Asplund K (1984) Eating after a stroke – towards an integrated view. *International Journal of Nursing Studies* 21, 93–99.
- Burton C (2000) Living with stroke: a phenomenological study. *Journal of Advanced Nursing* 32, 301–309.
- Carlsson E, Ehrenberg A & Ehnfors M (2004) Stroke and eating difficulties: long-term experiences. *Journal of Clinical Nursing* 13, 825–834.
- Carlsson E, Paterson PL, Scott-Finlay S, Ehnfors M & Ehrenberg M (2007) Methodological issues in interviews involving people with communication impairments after inquired brain damage. *Qualitative Health Research* 17, 1361–1371.
- Colaizzi PF (1973) *Reflection and Research in Psychology: A Phenomenological Study of Learning*. Kendall/Hunt Publishing Company, Dubuque, IA.
- Colaizzi PF (1978a) Psychological research as the phenomenologist views it. In *Existential-Phenomenological Alternatives for Psychology* (Valle R & King M eds). Oxford University Press, New York, NY, pp. 48–71.
- Colaizzi PF (1978b) Learning and existence. In *Existential-Phenomenological Alternatives for Psychology* (Valle R & King M eds). Oxford University Press, New York, NY, pp. 119–135.
- Ekberg O, Hamdy S, Woisard V, Wuttge-Hanning A & Ortega P (2002) Social and psychosocial burden of dysphagia: its impact on diagnosis and treatment. *Dysphagia* 17, 139–146.
- Ferro JM, Caeiro L & Santos C (2009) Post-stroke emotional and behavior impairment: a narrative review. *Cerebrovascular Disease* 27, 197–203.
- Gallagher S & Zahavi D (2012) *The Phenomenological Mind*, 2nd edn. Routledge, New York, NY.
- Hafsteinsdóttir TB & Grypdonck M (1997) Being a stroke patient: a review of the literature. *Journal of Advanced Nursing* 26, 580–588.
- Hong KS & Saver JL (2010) Years of disability adjusted life gained as a result of thrombolytic therapy for acute ischemic stroke. *Stroke* 41, 471–477.
- Jacobsson C, Axelsson K, Wenngren BI & Norberg A (1996) Eating despite severe difficulties: Assessment of post-stroke eating. *Journal of Clinical Nursing* 5, 23–31.
- Jacobsson C, Axelsson K, Osterlind PO & Norberg A (2000) How people with stroke and healthy older people experience the eating process. *Journal of Clinical Nursing* 9, 255–264.
- Jonsdóttir H & Ingadóttir TS (2011) Health in partnership: family nursing practice for people with breathing difficulties. *Qualitative Health Research* 21, 927–935.
- Kirkevold M, Bronken BA, Martinsen R & Kvinge K (2012) Promoting psychosocial well-being following stroke: developing a theoretically and empirically sound complex intervention. *International Journal of Nursing Studies* 49, 386–397.
- Klinke ME, Wilson ME, Hafsteinsdóttir TB & Jónsdóttir H (2012) Recognizing new perspectives in eating difficulties following stroke: a concept analysis. *Disability and Rehabilitation* 35, 1491–1500.
- Kubina L-A, Dubouloz C-L, Davis CG, Kessler D & Egan MY (2012) The process of re-engagement in personally valued activities during the 2 years following stroke. *Disability and Rehabilitation* 35, 236–243.
- Kumlien S & Axelsson K (2002) Stroke patients in nursing homes: eating, feeding, nutrition and related care. *Journal of Clinical Nursing* 11, 498–509.
- Mayo E, Wood-Dauphinee S, Côté R, Durcan L & Carlton J (2002) Activity, participation, and quality of life 6 months poststroke. *Archives of Physical and Medical Rehabilitation* 83, 1035–1042.
- McLaren SMG & Dickerson JWT (2000) Measurement of eating disability in an acute stroke population. *Clinical Effectiveness in Nursing* 4, 109–120.
- Medin J, Larson J, Von Arbin M, Wredling R & Tham K (2010a) Striving for control in eating situations after stroke. *Scandinavian Journal of Caring Sciences* 24, 772–780.
- Medin J, Larson J, Von Arbin M, Wredling R & Tham K (2010b) Elderly persons' experience and management of eating situations 6 months after stroke. *Disability and Rehabilitation* 32, 1346–1353.
- Medin J, Windahl J, Von Arbin M, Tham K & Wredling R (2012) Eating difficulties among patients 3 months after stroke in relation to the acute phase. *Journal of Advanced Nursing* 68, 580–589.
- Merleau-Ponty M (2012) *Phenomenology of Perception* (D.A. Landes, Trans.).

- Routledge, London (Original work published 1945).
- Miller EL, Murray L, Richards L, Zorowitz RD, Bakas T, Clark P & Billinger SA (2010) Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patients. *Stroke* 41, 2402–2448.
- Perry L (2004) Eating and dietary intake in communication impaired stroke survivors: a cohort study from acute stage hospital admission to 6 months post-stroke. *Clinical Nutrition* 23, 1333–1343.
- Perry L & McLaren S (2003a) Eating difficulties after stroke. *Journal of Advanced Nursing* 43, 360–369.
- Perry L & McLaren S (2003b) Coping and adaptation at six months after stroke: experiences with eating difficulties. *International Journal of Nursing Studies* 40, 185–195.
- Perry L & McLaren S (2004) An exploration of nutrition and eating difficulties in relation to quality of life at 6 months post stroke. *Health and Social Care in the Community* 12, 208–297.
- Perry L, Hamilton S, Williams J & Jones S (2012) Nursing interventions for improving nutritional status and outcomes of stroke patients: descriptive reviews of processes and outcomes. *Worldviews on Evidence-Based Nursing* 10, 17–40.
- Poels BJJ, Brinkman-Zijlker HG, Dijkstra PU & Postema K (2006) Malnutrition, eating difficulties and feeding dependence in a stroke rehabilitation centre. *Disability and Rehabilitation* 28, 637–643.
- Salter K, Hellings C, Foley N & Teasell R (2008) The experience of living with stroke: a qualitative meta-synthesis. *Journal of Rehabilitation Medicine* 40, 595–602.
- Sandelowski M (1995) Sample size in qualitative research. *Research in Nursing and Health* 18, 179–183.
- Vuorisalmi M, Lintonen T & Jylha M (2006) Comparative vs. global self-rated health: associations with age and functional ability. *Aging Clinical and Experimental Research* 18, 221–217.
- Westergren A (2006) Detection of eating difficulties after stroke: a systematic review. *International Nursing Reviews* 53, 143–149.
- Westergren A (2008) Nutrition and its relation to mealtime preparation, eating, fatigue and mood among stroke survivors after discharge from hospital - a pilot study. *Open Nursing Journal* 2, 15–20.
- Westergren A, Karlsson S, Andersson P, Ohlsson O & Hallberg IR (2001a) Eating difficulties, need for assisted eating, nutritional status and pressure ulcers in patients admitted for stroke rehabilitation. *Journal of Clinical Nursing* 10, 257–269.
- Westergren A, Ohlsson O & Rahm Hallberg I (2001b) Eating difficulties, complications and nursing interventions during a period of three months after a stroke. *Journal of Advanced Nursing* 35, 416–426.
- Zahavi D (2003) *Husserl's Phenomenology*. Stanford University Press, Stanford, CA.

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